Recommending Integration into the Community: How Long Must History Repeat Itself?

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“There is nothing new in the world except the history you do not know.”

– Harry S Truman (1884-1972)

A brief timeline:

- 1773 – First public MH facility in US (ESH)
- 1923 – First Virginia “Mental Hygiene Clinic” established
- 1942 – Permissive legislation creates the Virginia Clinic System (Department established) DMHH
- 1968 – First 2 Community Service Boards appointed
- 1971 – First services offered by a Chapter 10 CSB funded

Summary of DMHMRSAS Philosophical Statements on Community-Based Services

- 1949 to 1998
- 205 studies, reports, recommendations

40 years of Commissions
A brief timeline:

- 1963 Willey Commission
- 1970 Hirst Commission
- 1980 Bagley Commission
- 1986 Emick Commission
- 1996 Hall/Gartland Commission
  (HJR 240 Joint Subcommittee)
- 1998 Hammond Commission
- 2006-08 ??? Commission

Willey Commission (1963)

- 75 member “blue ribbon” commission conducted series of meetings across the state.
- report containing 65 recommendations - among them the expansion of community mental health centers and clinics.
- called upon the General Assembly to fulfill its historic responsibility as the major financier for MH services, through increased appropriations for clinic services.

Hirst Commission (1970)

- “proposes a totally new direction and attitude”

- “successful improvement of mental health services…requires a total commitment to the concept of a coordinated system of care focused on the patient rather than the agency or institution.”

Bagley Commission (1980)

- "called for treatment, training and care in the least restrictive environment"
- "urged establishment of services to integrate persons with mental disabilities into the community"
- stated that "funds should follow the client"

Emick Commission (1986)

- “concluded that the difficulties associated with de-institutionalization could be attributed primarily to a lack of community resources
- recommended the state should be committed to developing a single system of care in which community services boards would be granted greater service and fiscal accountability for the delivery of programs to clients.
- This included a single financing system in which boards would be responsible for using funds to provide both community services and hospital services.”

Hall/Gartland Commission HJR 240 (1996)

- 112 recommendations:
  - increase consumer and family participation
  - strengthen the state-local partnership
  - renew Virginia's commitment to community-based system
  - encourage relationships with the private sector
  - enhance system responsiveness and accountability
  - streamline procedures/improve efficiencies
  - incorporate new technologies and intensive service approaches
  - ensure respect for human rights of consumers and families

Hammond Commission (1998)

- Report summarized 8 guiding principles:

- Including principle #4 – “Virginians should strive to improve the possibilities for people with mental disabilities to lead independent lives in a community.

Nothing new under the sun: "**Reinvestment**"

- "Legislature should adopt a "**reinvestment**" policy resolution to ensure state controlled funds provided to serve mentally disabled persons remain in the state-local service system – regardless of the location of the service recipient."

  » Joseph Bevilacqua, Ph.D. (Report to the Emmick Commission on De-institutionalization; July 26, 1985)

Nothing new under the sun: "**Reinvestment**"

- Gubernatorial Candidate Gerald L. Baliles (October 1985):
- "I will work to assure that community-based treatment and care is a priority goal. I will seek a share of general revenues for our mentally disabled citizens appropriate to their needs and I will work to assure that funds saved through reductions in the state's institutional population are reinvested in community programs for the mentally disabled."

Nothing New Under the Sun: "**Transformation**"

- "Cooperation, Coalition, Transformation: An Agenda for the 90's"

- Conference title and proceedings sponsored by the DMHMRSAS state board and Coalition of Mentally Disabled Citizens of Virginia (September 25-26, 1989)

Nothing New Under the Sun: **Budget emphasis on Community Services**

- "Additional Community Services proposal is the 'cornerstone' of the DMHMRSAS biennial budget initiative."

  – Virginia Comprehensive State Plan (September 1, 1987)

Why do we have to keep repeating the recommendation for "Community Integration?"

Why do we have to keep repeating the recommendation for "Community Integration?"

- Lack "Recovery" Vision
- Lack conviction
- Lack the right questions

What is Recovery?

- Current Notion dates back to mid-1980's
  - Harding's (1987) Vermont Longitudinal Study that showed the course of severe mental illness was NOT inevitable deterioration.
  - Several first person accounts of "recovery"
    - Deegan (1988)
    - Fisher (1992)
    - Copeland (1994)

Tsuang et al. Study

- Sample size: 186
- Average length of follow-up: 35 years
- Rates of significant improvement or recovery for schizophrenia:
  - ✓ **46%**

Tsuang, M.T., Woolson, R.F., & Fleming, J.A. (1979). Long-term outcome of major psychoses: 1. Schizophrenia and affective disorders compared with psychiatrically symptom-free surgical conditions. Archives of General Psychiatry, 36, 1295-1301.

(From Deegan' Lessons in Recovery and Resilience)

Harding et al. Study

- Sample size: 269
- Average length of follow-up: 32 years
- Rates of significant improvement or recovery for schizophrenia:
  - ✓**62-68%**

Harding, C.M., Brooks, G.W., Ashikaga, T., Strauss, J.S., & Breier, A. (1987). The Vermont longitudinal study of persons with severe mental illness: 1. methodology, study, sample, and overall status 32 years later. American Journal of Psychiatry, 144(6), 718-726.

Harding, C.M., Brooks, G.W., Ashikaa, T., Strauss, J.S., & Breier, A. (1987). The Vermont longitudinal study: II. Long-term outcome of subjects who retrospectively met the criteria for DSM-III schizophrenia. American Journal of Psychiatry, 144(6), 727-735.

(From Deegan' Lessons in Recovery and Resilience)

Ogawa et al. Study

- Sample size: 140
- Average length of follow-up: 22.5 years
- Rates of significant improvement or recovery for schizophrenia:
  - ✓ **57%**

Ogawa, K, Miya, M., Watarai, A., Nakazawa, M., Yuasa, S. & Utena, H. (1987). A long-term follow-up study of schizophrenia in Japan with special reference to the course of social adjustment. British Journal of Psychiatry, 151, 758-765.

(From Deegan' Lessons in Recovery and Resilience)

DeSisto et al. 1995

- Sample size: 269
- Average length of follow-up: 35 years
- Rates of significant improvement or recovery for schizophrenia:
  - ✓ **49%**

DeSisto, M., Harding, C.M., Ashikaga, T., McCormick, R., & Brooks, G.W. (1995). The Maine and Vermont three-decade studies of serious mental illness: Matched comparison of cross-sectional outcome. British Journal of Psychiatry, 167, 338-342.

DeSisto, M., Harding, C.M., Ashikaga, T., McCormick, R., & Brooks, G.W. (1995). The Maine and Vermont three decade studies of serious mental illness: II. Longitudinal course comparisons. British Journal of Psychiatry, 167, 338-342.

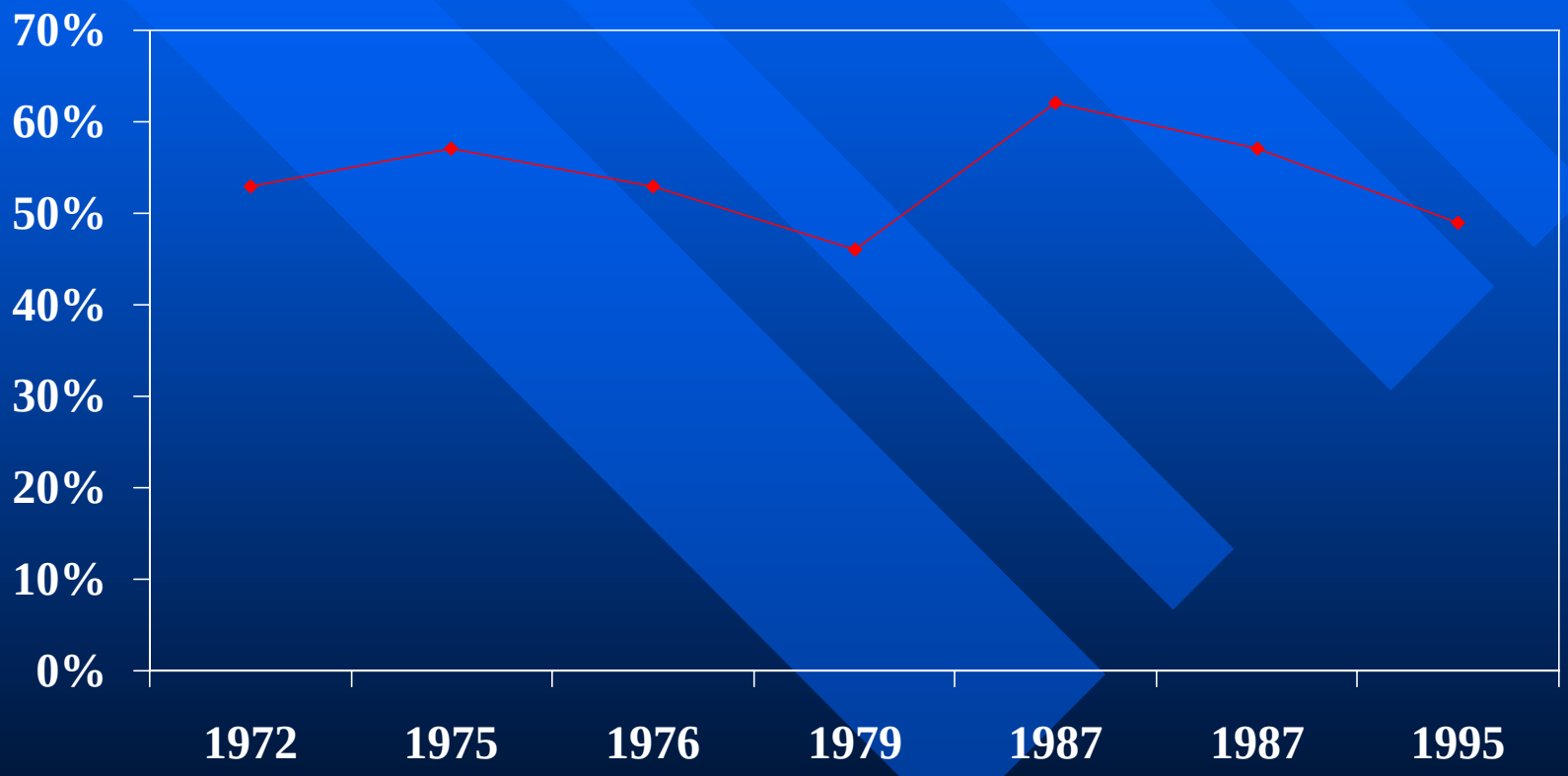
(From Deegan' Lessons in Recovery and Resilience)

Harding et al. 1987 Study

- Recovery defined as four criteria:
  - Having a social life similar to others in the wider community
  - Holding a paying job or volunteering
  - Being symptom free
  - Being off of psychiatric medications
- 62% of people diagnosed with schizophrenia met 3 of the 4 criteria

(From Deegan' Lessons in Recovery and Resilience)

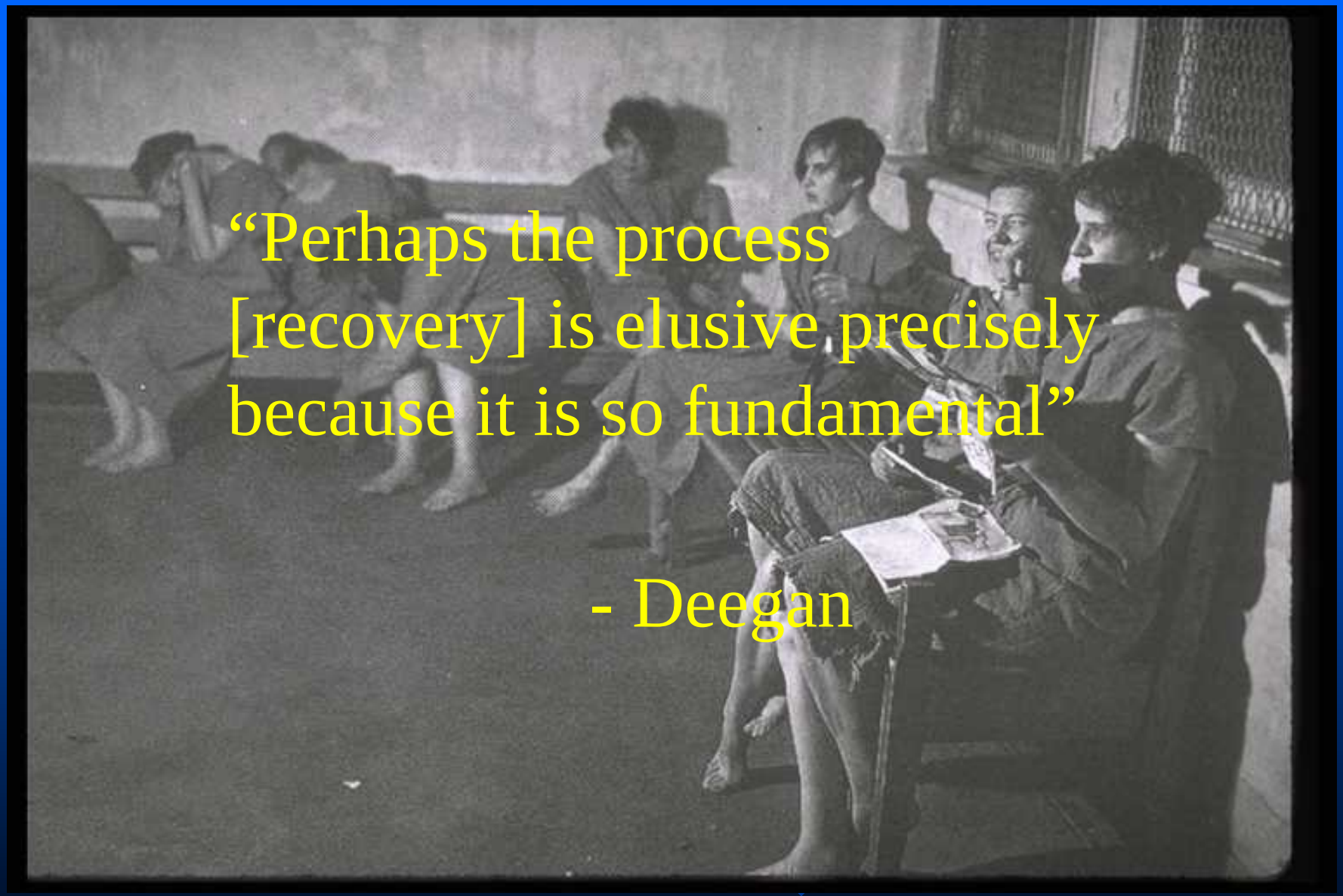
Longitudinal Studies: Recovery Rates



(From Deegan' Lessons in Recovery and Resilience)

What is Recovery?

- Patricia Deegan, Ph.D.
- *Recovery: The Lived Experience of Rehabilitation* Psychosocial Rehab Journal (1988)


“Perhaps the process [recovery] is elusive precisely because it is so fundamental”
- Deegan

DSM-IV-TR (2000)

- "… an accurate summary of the long-term outcome of Schizophrenia is not possible. Complete remission (i.e., a return to full premorbid functioning) is probably not common in this disorder. Of those who remain ill, some appear to have a relatively stable course, whereas others show a progressive worsening associated with severe disability."

DSM-III (1980)

- “The most common course [of schizophrenia] is one of acute exacerbations with increasing residual impairment between episodes.”

“Dramatic improvement in a patient with a diagnosis of schizophrenia was regarded by many clinicians as evidence of original misdiagnosis”

- Rund, BR; Fully Recovered Schizophrenics: a retrospective study of some premorbid and treatment factors. Psychiatry 1990; 53:127-139

Biological Psychiatry

- "Relatively little attention has been paid to the role of neuro-degenerative processes [in Schizophrenia] despite the clinical course of the illness and the fact that most patients experience varying degrees of behavioral and cognitive deterioration."

  – J. Lieberman, Biological Psychiatry (1999)

Kaplan and Sadock's Comprehensive Textbook of Psychiatry, 7th edition (2000)

- "Studies in Europe, the United States, Japan that followed up persons who experienced disabling forms of schizophrenia during adulthood found, 20 to 40 years later, a remarkable 50 to 66 percent functioning actively in their communities with few symptoms, a reasonably good subjective quality of life, and only limited dependence on professional caregivers." (R. Liberman)

Kaplan and Sadock's Comprehensive Textbook of Psychiatry, 7th edition (2000)

- "These findings have spurred interest in psychiatric rehabilitation as a way to facilitate social and symptomatic recovery of seriously mentally ill persons."

•(R. Liberman)

Remission in Schizophrenia:
Proposed Criteria and Rational for consensus

- American Journal of Psychiatry, March 2005
- Nancy C. Andreasen, M.D., Ph.D., et al
- Remission in Schizophrenia Working Group
- “To Develop a Consensus Definition of Remission as applied to Schizophrenia”

Remission in Schizophrenia:
Proposed Criteria and Rational for consensus

- "The need for such a definition is timely because…evidence that traditional predictions of generally poor outcome may have been overstated."

  - Nancy C. Andreasen, M.D., Ph.D., et al

  Am J Psychiatry 2005; 162:441-449

Recovery

- Has become a popular concept in guiding system reform at both Federal and State level
  - President's New Freedom Commission Final Report
  - Surgeon General's Report
  - SAMHSA vision
  - Commonwealth of Virginia DMHMRSAS Strategic Plan and Vision for Restructuring

The President's New Freedom Commission on Mental Health

Achieving the Promise:

Transforming Mental Health Care in America

President's New Freedom Commission on Mental Health

Achieving the Goal: Recommendation 2.2

Involve consumers and families fully in orienting the mental health system toward recovery

Vision Statement:

"We envision a future when everyone with a mental illness will recover…"

DMHMRSAS'
Integrated Strategic Plan
strongly emphasizes
Recovery, Empowerment, and
Self-Determination
as the key factor in transforming
our service system.

The term “Recovery” has led to Confusion/Conflict

- Consumers
  - Who are expected to recover
- Professionals and Policy Makers
  - Who are expected to help them

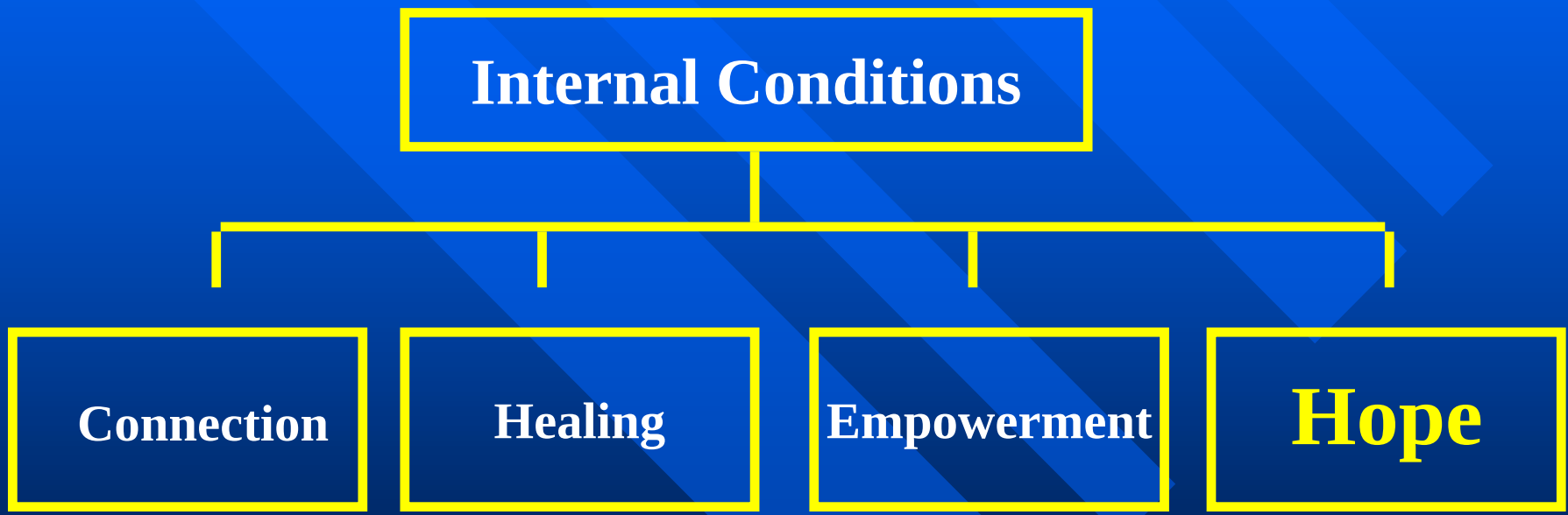
What is Recovery?

A Conceptual Model

Jacobson and Greenley; Pscych Services; April 2001

- Internal Conditions
  - Attitudes,experiences and processes of change of individuals who are recovering
    - » Hope
    - » Healing
    - » Empowerment
    - » Connection
- External Conditions
  - Circumstances, events, policies and practices that may facilitate recovery
    - » Human Rights
    - » A positive culture of healing
    - » Recovery-oriented services

Recovery

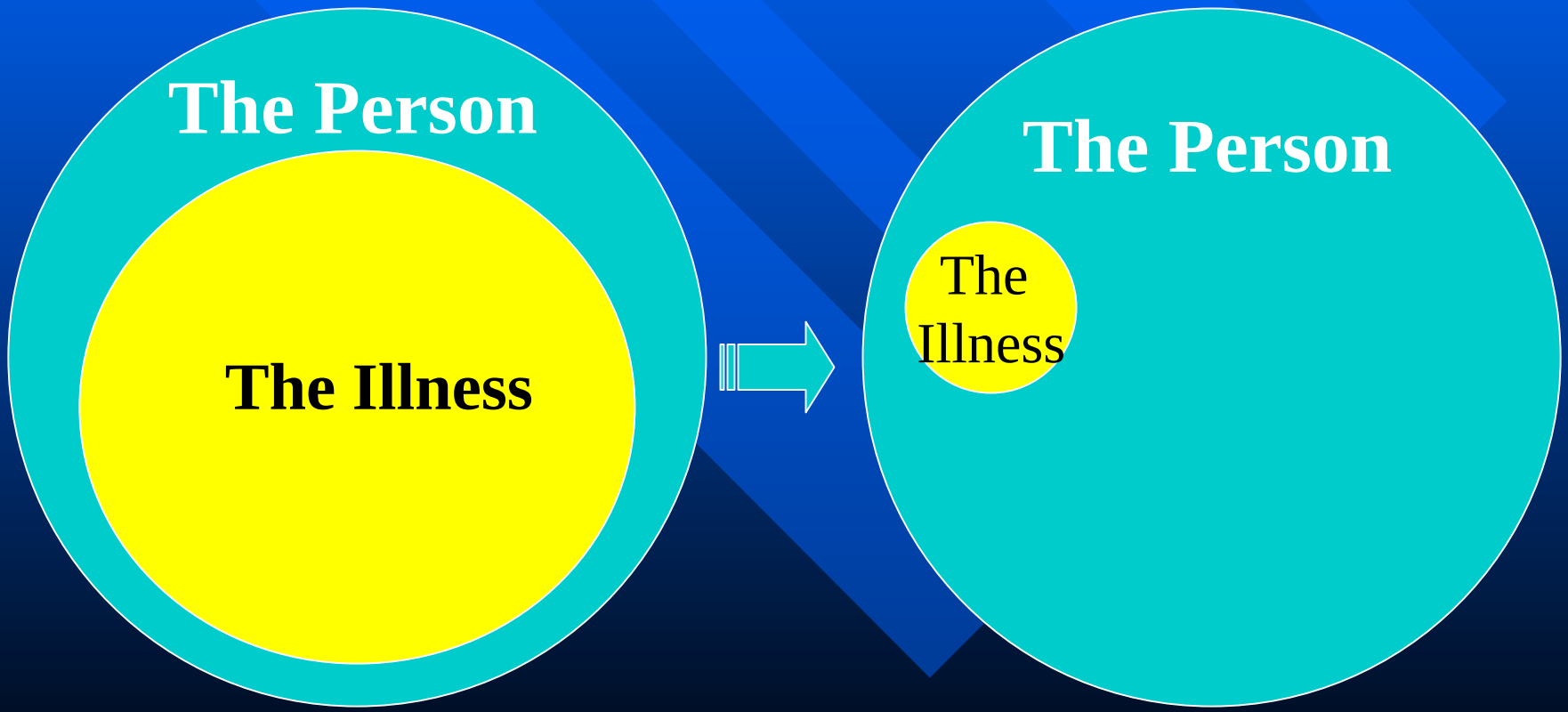


Jacobson: N, A Conceptual Model of Recovery

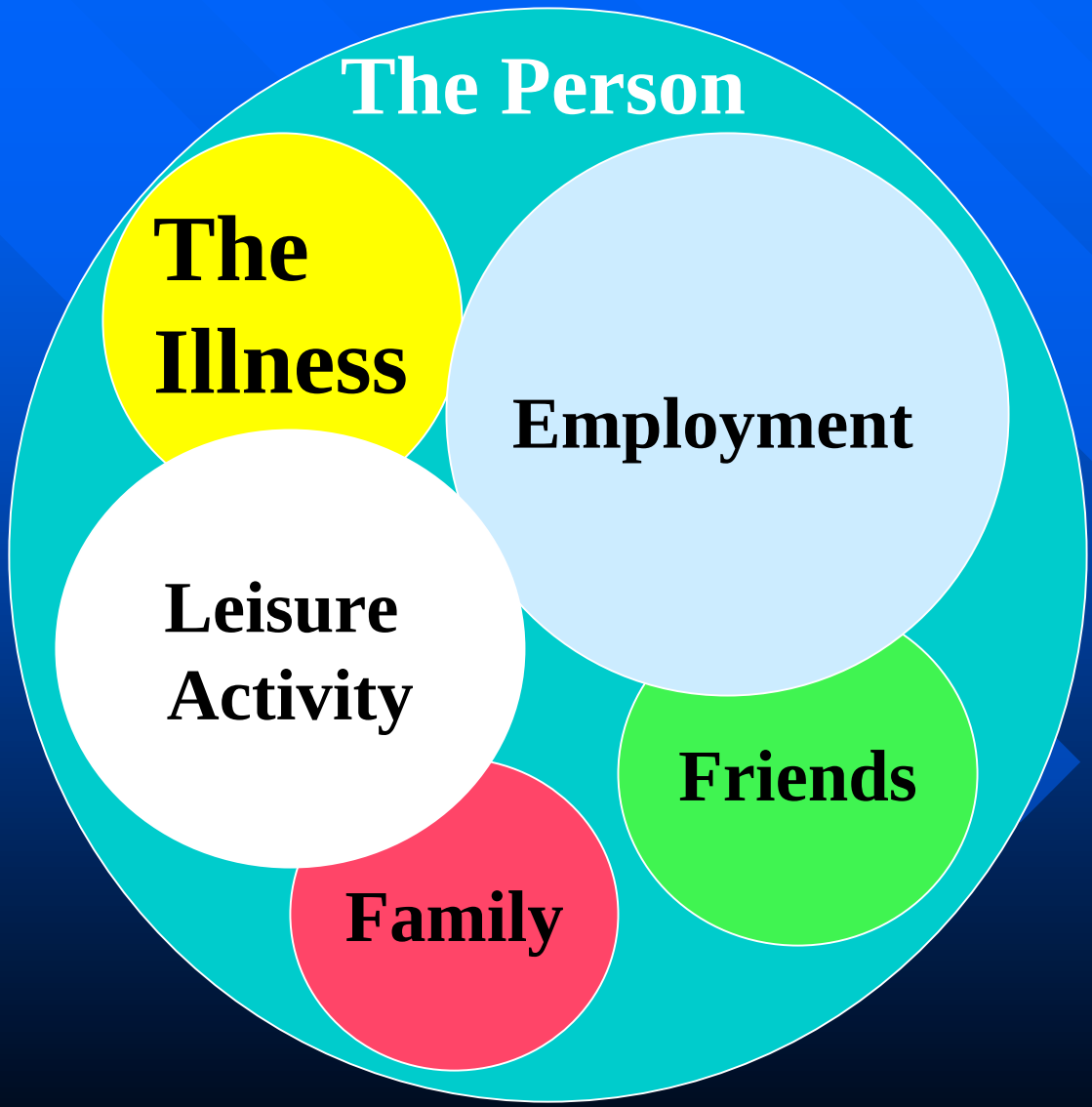
- Connection: rejoining the social world or "getting a life"
- Recovery is a profoundly social process
- For many, this means helping others who are also living with mental illness
  - Becoming provider
  - Peer support
  - Advocate
  - Telling personal story

- Healing
  - Recovery is NOT synonymous with ‘cure’
  - Recovery concept is not necessarily a return to “normal”
  - Two components of Healing in Recovery:
    - » Defining the self apart from illness
    - » Control

Process of Recovery



Process of Recovery



I’ve finally decided,
With some inner will, -
That I’m too busy,
To be mentally ill,
I take my meds,
And try to think,
Sitting and talking,
With the shrink,
I am so busy,
I don’t have time,
To think about it,
All the time.
I’m so busy,
Be assured,
I won’t even noticed,
If I am cured.

- Dylan Abraham

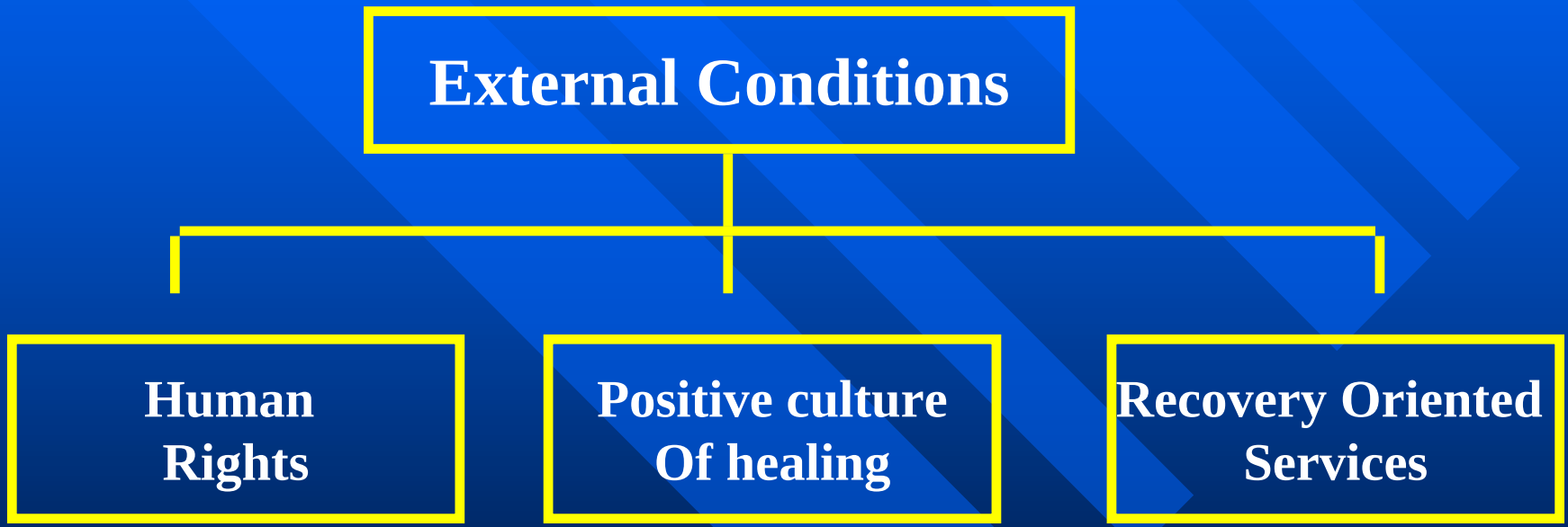
- Empowerment: a corrective for the lack of control and dependency that many consumers develop after long-term interactions with the mental health system
- 3 Components
  - Autonomy
    - » Knowledge
    - » Self-confidence
    - » Availability of meaningful choices
  - Courage
    - » Willingness to take risks
    - » To speak in one's own voice
    - » To step out of safe routines
  - Responsibility

- Hope: the individual's belief that recovery is possible

- Attitudinal components of Hope are:
  - **Recognizing, accepting that there is a problem**
  - **Committing to change**
  - **Focusing on strengths rather than on weakness or possibility of failure**
  - **Looking forward rather than ruminating on past**
  - **Celebrating small victories**
  - **Reordering priorities**
  - **Cultivating optimism**

(Jacobson and Greeley)

Models of Recovery



Jacobson: N, A Conceptual Model of Recovery

External Conditions of Recovery

- Human Rights
  - Reducing/eliminating stigma
  - Protecting rights of persons in service system
  - Providing equal opportunities (education, housing, employment
- A Positive Culture of Healing
  - Tolerance, listening, empathy, compassion, respect, safety, trust
- Recovery Oriented Services
  - Attitude of the professionals who provide them
  - Partnership, collaboration

“Recovery” vision not clear for many clinicians

- Poorly defined
- Inspiring Concept, but abstract
- Not research based at this point
- Raises questions:
  - Does “Recovery” vision raise false hopes?
  - Is “Recovery” relevant for only bright, educated, less severely ill?
  - Will some consumers with ongoing symptoms blame themselves for not recovering?

Implications for Providers

(Torrey and Wyzik, Comm. Mental Health Journal, April 2000
The Recovery Vision as a Service Improvement Guide)

- People with psychotic illnesses and other severe mental illnesses have written about their life experiences
- Customer feedback is an essential ingredient of healthcare quality improvement
- Consumer's insights should be valuable to providers who wish to improve services

Implications for Providers

(Torrey and Wyzik, Comm. Mental Health Journal, April 200
The Recovery Vision as a Service Improvement Guide)

- "For the authors of this report, concerns about the recovery vision have diminished over time. Through reading the consumer literature, talking to consumers, and applying our growing understanding of the the recovery vision…we have become convinced that the recovery vision's hope promoting benefits outweigh its potential problems."

Consumer Feedback: Themes of Recovery Narratives

(Torrey and Wyzik)

- Recovery is characterized by growth out of:
  - Hopelessness
  - Powerlessness
  - Illness dominated sense of self

Recovery Vision Implementation:

(Torrey and Wyzik)

- Promoting Hopefulness
  - The restoration of morale
- Supporting consumers' efforts to take personal responsibility for their health
- Helping Consumers develop broad lives that are not illness-dominated

The Disease Centered Model

- **Professional Role**
  - Hierarchical
  - Paternal
  - In-charge
  - Holds the important knowledge
  - Responsible for treatment
  - Disease is focus
- **Patient's Role**
  - Subservient
  - Obedient
  - Passive
  - Recipient of knowledge
  - Responsible for following treatment
  - Host of the disease

Recovery: Person Centered Model

- **Person's Role**
  - Personal power
  - Personal knowledge
  - Personal responsibility
  - Person in context of life is the focus
  - Person is self-determining
- **Professional Role**
  - Power sharing
  - Exchange information
  - Shared decision-making
  - Co-investigator
  - Professional is expert consultant on journey

Practical Examples of the Recovery Vision:

- Revision of FRP process
- Seclusion and Restraint reduction
- Policy changes on Pass/leave
- LOS reduction
- TOVA vs Mandt training

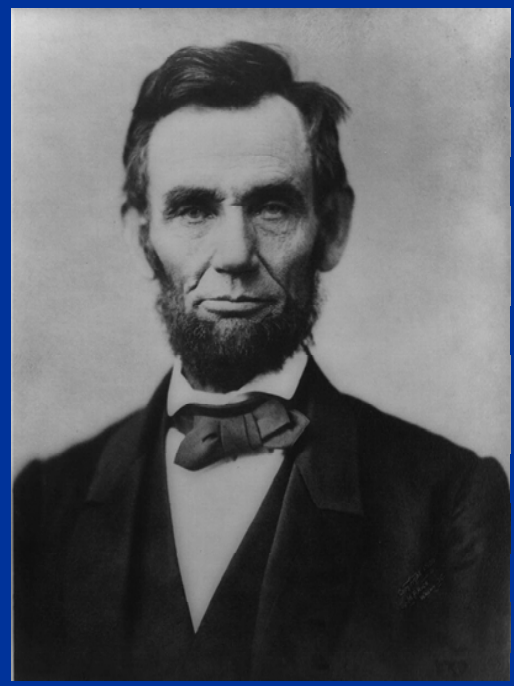
TOVA vs Mandt training/interventions

"Violence is the language of the unheard"

-- Martin Luther King, Jr.

TOVA vs Mandt training/interventions

"Nearly all men can stand adversity, but if you want to test a man's character, give him power."



-- Abraham Lincoln

Practical Examples of the Recovery Vision:

- Crisis Stabilization and other community alternative capacity enhancements vs increasing “traditional” inpatient beds
- Crisis Intervention Teams (CIT)
- Mental Health Courts
- Increased involvement of consumers as providers of care

Case Example: Misdemeanant NGRIs (MNGRI)

- 25% of total NGRI population (72 of 320)
- Prior to Code Change, Institutional confinement was indefinite (Average LOS: 1087 days)
- 2002 Virginia Code change limited NGRI status to 1 year
  - At end of year:
    - » released by courts
    - » civil commitment

Misdemeanant NGRIs

- 36 MNGRI in DMHMRSAS facilities in 2002
  - 22 released conditionally in 10/2002
  - 16 civilly committed

Misdemeanant NGRIs

- **Results of MNGRI law change:**
  - **36 MNGRIs placed on CR between 7/02 & 4/05**
  - **26 are in the community:**
    - » 11 have been Unconditionally Released by the Courts
    - » 14 have remained on Conditional Release without revocation
    - » 1 MNGRI was revoked and later unconditionally released
  - **7 have been revoked and remain in the hospital**
    - » **Revocation for non-adherence to plan, not new crimes**

Why do we have to keep repeating the recommendation for "Community Integration?"

- Lack "Recovery" Vision
- Lack conviction
- Lack the right questions

Lack Conviction

- Does society really want to see everyone in their communities?
- Are we really committed to allowing others to have “a life like ours”?
- Do we really believe it is a human right?
- Are we really willing to “accommodate”:?
  - Different appearances
  - Different illnesses
  - Different abilities and IQ’s
- Can we allow more people to take risks and sometimes fail?

Autobiography in Five Short Chapters

by Portia Nelson

Chapter One

I walk down the street
There is a deep hole in the sidewalk.
I fall in.
I am lost... I am helpless.
It isn't my fault.
It takes forever to find a way out.

Chapter Two

I walk down the same street.
There is a deep hole in the sidewalk.
I pretend I don't see it.
I fall in again.
I can't believe I am in this same place.
But, it isn't my fault
It still takes a long lime to get out.

- Chapter Three

I walk down the same street.

There is a deep hole in the sidewalk

I see it is there.

I still fall in. It's a habit.., but.

my eyes are open.

I know where l am.

It is my fault.

I get out immediately.

- Chapter Four

I walk down the same street.

There Is a deep hole in the sidewalk.

I walk around it.

Chapter Five

I walk down another street.

Why do we have to keep repeating the recommendation for "Community Integration?"

- Lack "Recovery" Vision
- Lack conviction
- Lack the right questions

We Lack the Right Questions

- Have not done studies, asked questions using the “recovery, empowerment, self-determination” model.

- “Accurate information on care and treatment practices, outcome/results, cost, satisfaction of the people and families served” (Hammond Commission)

What everyone wants…

- "A life like yours"
- "Something to do…Someone to Love."
  - » George Valliant

What should we ask…

- Have the services that you have received helped you get something meaningful to do with your time?
  - Volunteering, peer support
  - Employment
  - Establishment of residence/home
  - Being a part of a group, family, or community
- Have the services that you have received helped you love or be loved?
  - helped you find someone to care for
  - helped someone care for you

“Those who cannot learn from history are doomed to repeat it.”

– George Santayana

“History is more or less bunk. It’s tradition. We don’t want tradition. We want to live in the present and the only history that is worth a tinker’s damn is the history we make today.”

– Henry Ford